

EXECUTIVE SUMMARY

Healthcare for Youth with Neurodevelopmental Disabilities:

A Consensus Statement
Plain Language



Summary

“SAFE” is a set of statements made by doctors and other experts who worked together to make sure that kids with certain disabilities called “NDDs” get great care in hospitals and clinics.

Background

About 1 in 6 people under 18 years old has a neurodevelopmental disability, or “NDD” for short. NDDs refer to a group of conditions that impact our brains. This can affect things like talking, moving, or how someone behaves. Young people with NDD are more likely to need more support. These can be physical needs, or they might need help with their mental health.

Both children and adults who have NDD often have trouble getting medical care. They are also more likely to have bad things happen to them during medical care. Things like not getting the right care, getting hurt, or being forcibly separated from others. Sometimes even being forcibly made to stop moving. If this happens to people with NDD, they may not want to go to a doctor or hospital. Over time it can be very bad for their health and well-being.

There are lots of reasons why this can happen. Some doctors may not know enough about NDDs. Sometimes communication is hard. Some people on a health care team may have a bias called “structural ableism”. This is when people do not treat those with disabilities the same as others.

SAFE Initiative

Two organizations (DBPNet and AUCD) came up with an “initiative”, or plan, to improve this. They called this initiative “**Supporting Access For Everyone**”, or “SAFE” for short. They got together medical care people, adults with NDD, and their caregivers. Then, they held a large meeting that the public could attend. 40 people spoke at the meeting. After that, they all came together to agree on ways to improve care for youth with NDDs.

The final “consensus statement” (Weitzman et al., 2024) is published in a journal called *Pediatrics*; go to safedbp.org for more information.

Foundational Premises of SAFE Care

SAFE care is:

- Care that individuals understand and want;
- Only for that person and changes with their needs;
- Accessible for their entire life;
- Fair and respectful;
- Defined by how the patients feel during the visit, how good the care is, and how much impact it has on their health.
- **Not** only defined by how good people *think* the care is.
- **Not** defined by how much money the care may have cost.

SAFE care reduces or eliminates:

- Risk of physical and emotional harm to people. This includes accidents and injuries. As well as being forcibly separated from others, and being forcibly made to stop moving.
- Care that isn’t complete, or care that is not good enough.
- “Foregone care”, which means care that you may need, but don’t use. This can lead to untreated conditions. It can also lead to more people having certain health conditions.

*“Find out what the person in front of you needs...
and build the care and the plan around it.”*

- Patrick Forgey, Advocate

SAFE Consensus Statements

There are 5 “domains,” or areas, that highlight the most important areas for improving healthcare for youth with NDDs. Each domain includes at least one of “statements.” “Statements” in this case are the ideas that everyone in the SAFE initiative agreed on.

The first domain is “Training”. There is one statement. It says that all healthcare workers need to learn and know about NDDs. They also have to understand what could happen to the patient if they use “non-SAFE” practices.

The second domain is “Communication”. It has 2 statements. The first says communication needs to be accessible to everyone in health settings. The second says care professionals have to include patients with NDD and their families in “supported decision making” that benefits them throughout their lives. What is “supported decision making”? It means giving someone the tools or help they need to make a decision. This looks different for everyone depending on their needs.

The third domain is “Access and Planning”. It has 2 statements. The first says care needs to be for one person. The medical care team, patients, and families should work together to develop care for their needs. The second says places like hospitals need to meet the needs of people with NDD. This includes being able to understand their options for care. Or, having access to other people who may help patients with NDD.

The fourth domain is “Diversity, Equity, Inclusion, Belonging and Anti-Ableism”. It has 2 statements. The first says that a hospital or other care settings needs to include people with NDD in their DEI efforts. “DEI efforts” are things that try to make sure everyone is included and listened to. The second statement says recognizing structural ableism is important. And, that marginalized people are more likely to have disabilities.

The last domain is “Policy and Structural Change”. It has 3 statements. The first says that places like hospitals need to find out the best ways to care for people with NDDs. Then, they need to create plans to improve them based on what they find. These plans have to be “sustainable”, which means they have to be able to continue. They also have to be specific to their own needs as a hospital.

The second statement says that places like hospitals have to keep improving. This means their efforts to help people with NDDs, to make sure services are quick, fair, and effective.

Finally, the last statement. It says that places like hospitals, along with people with NDDs, need to advocate for change in rules and policies. For example, laws that change how services are paid for at a hospital. Or, laws that improve care for people with NDD.

Call to Action

Large, sweeping changes are required to improve health outcomes for people with NDDs. What are these changes? Things like changing how we think about people with NDDs. Or, putting money into learning new things about NDDs.

People with NDDs need to be involved in work like this, and their families too! They need to work with the entire healthcare community.

Everybody needs to have healthcare that they can access. Everybody needs to have healthcare that is compassionate. Everybody needs to have healthcare that works well for them.

*The work of **SAFE** is just beginning!*



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